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APOYANDO EN SALUD SEXUAL Y VIH/ SIDA

International
HIV/AIDS Alliance

Research Summary

December 2000



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The Involvement of People Living with HIV/AIDS
in the Delivery of Community-based Prevention,
Care and Support Services in Ecuador

Introduction

This is a summary of the results of a research study undertaken in Ecuador between June 1999 and May 2000. This research forms part of an international diagnostic study on the involvement of People Living with HIV/AIDS (PLHA) in the delivery of community-based prevention, care and support services in developing countries, which is being conducted in four countries: Burkina Faso, Ecuador, India and Zambia. This diagnostic study is one of the activities of the Horizons International Operations Research Project, funded by USAID and implemented by the Population Council and five other organisations, including the International HIV/AIDS Alliance, which coordinated this study.

The objectives of the study are: to describe current types of PLHA involvement; to identify factors encouraging or limiting PLHA involvement in non-governmental organisations (NGOs); and to explain the impact PLHA involvement has on the quality and effectiveness of community-based prevention and care and support services. Gender is a cross-cutting issue throughout the study.

The goal of the operations research is to develop meaningful forms of PLHA involvement and, more generally, to help participating NGOs to identify the strengths and weaknesses of their activities and services in order to improve them.

Study Methodology

In order to study PLHA involvement at the community level in Ecuador, four¹ NGOs were invited to participate in the study, based on the following criteria:

- NGOs currently working in HIV/STI prevention and PLHA care and support;
- A cross-section of NGOs with different levels of PLHA involvement in their activities, or the possibility of such;
- NGOs interested in the issue of PLHA involvement;
- NGOs receiving support from the International HIV/AIDS Alliance's linking organisation in Ecuador, Corporación Kimirina.

¹ A fifth NGO was selected but subsequently withdrew from the study.

The Participating NGOs

Dios, Vida y Esperanza Foundation

This NGO is based in Guayaquil. It has provided care and support services since 1992, largely to PLHA but also to affected people. Services include: medical care, provision of medicines, discounted referrals to clinical laboratories, pre- and post-test counselling, psychological and socio-economic support and home visits. It is also involved in prevention and awareness-raising activities.

The NGO evolved from a PLHA self-help group and, right from the start, has provided a space for PLHA involvement. A diverse team of health workers, who are specialists in HIV/AIDS and related issues, run the organisation.

Esperanza Foundation

This NGO is based in Quito and has been working in HIV/AIDS since 1992. It was set up by a team of health and social workers and provides STI and HIV/AIDS prevention services for sex workers in the city of Quito. A significant part of its work involves defending the rights of sex workers and supporting the sectorial strengthening of the sex worker community.

Esperanza also provides modest care and support services. To date, PLHA have been service users only although there is now interest in creating spaces for PLHA involvement.

Vivir Foundation

This NGO is based in Quito and began work in 1990 as a PLHA self-help group. It is now made up of affected people, particularly relatives of the founding PLHA. Vivir has a team of social and health workers and it is involved in prevention and care and support of PLHA and affected people. It has a particular focus on medical care, supplying discounted medicines, discounted referrals to clinical laboratories and pre- and post-test counselling.

Some PLHA are involved in the organisation but involvement is infrequent.

Siempre Vida Foundation

This NGO is based in Guayaquil and is made up of PLHA and affected people who have been working together since 1994. Its main activities include direct services: pre- and post-test counselling, psychological support and buddy support, a self-help group, telephone support and information; and indirect services: referrals to health workers with whom the NGO has connections for specialised medical care, free or discounted provision of medicines and discounts at clinical laboratories. The organisation also undertakes prevention and awareness raising activities on request, with the visible involvement of PLHA. The most active members of the association are involved in advocacy work.

PLHA, along with affected people, are involved both in service delivery and the management and planning of activities.

This sample of four organisations represents 40% of those NGOs working in both PLHA care and support and HIV/AIDS prevention in Ecuador².

Some 115 service providers and users from the four NGOs participated in interviews and/or focus groups, representing between 43% and 100% of the volunteers and staff of each organisation and between 14% and 22% of the PLHA and affected people using the services of each of the four NGOs.

Interviews and focus groups were also conducted with other categories of people: relatives of the PLHA who are providing services in the NGOs, PLHA who are neither NGO service providers nor users, health workers, decision makers in the health sector and community leaders (57 people).

A total of 172 informants participated in 126 interviews and 15 focus groups, which were carried out by a team of three researchers.

Other qualitative techniques for information gathering were used, such as visual appraisal techniques and observation. The qualitative data was supplemented with information gathered by means of a short questionnaire that was handed out primarily to the participating population of the four NGOs. The questionnaire enabled basic quantitative data to be gained on the socio-demographic profile of this population.

As well as being qualitative, the methodology was extremely participatory. Members of the four organisations participated actively in each stage of the study: methodological design, data collection, data validation and analysis, including a data analysis workshop, formulation of the report of each organisation's results (profile) and, finally, dissemination of the results.

This summary presents the national context in which civil society has mobilised around HIV/AIDS in Ecuador, the different types of PLHA involvement that have been identified on the basis of the sample of organisations involved in the study, some of the advantages and disadvantages of the different forms of involvement, the impact involvement has on PLHA, on the organisations and on the services they offer and, finally, the factors that limit or encourage involvement. In addition, some of the results of the research relating to gender and involvement are also presented.

² There are approximately 10 NGOs working in both prevention and care in Ecuador.

HIV/AIDS in Ecuador

Epidemiology of HIV/AIDS in Ecuador

UNAIDS estimates that, by the end of 1999, there were 19,000 adults living with HIV/AIDS in Ecuador, ie 0.29% of the adult population. This level of prevalence is considered low. Nevertheless, the epidemic is continuing to grow.

The main mode of transmission is sexual (84%) and an increase in prevalence amongst the heterosexual population has been observed (60% of HIV infections in 1999). The majority of those infected by HIV continue to be men (64%) but a significant increase amongst women and teenagers has been observed. The coastal provinces are the worst affected. (Ministry of Public Health, National AIDS Programme: 2000).

Attitudes and Behaviour towards PLHA

A study carried out amongst teenagers in 1998 showed that the majority considered those at greatest risk of contracting AIDS were sex workers, homosexuals and heterosexual men with multiple sexual partners (Cemoplaf: 1998). This study showed that people continue to see AIDS as a problem affecting only other people, particularly those belonging to socially marginalised groups. Such perceptions contribute to the stigmatisation of PLHA and the study's informants provide many concrete examples of stigma and discrimination against PLHA in Ecuador. However, the study also shows that people who have been informed about AIDS and who know PLHA have overcome attitudes of rejection and discrimination.

The State Response to the HIV/AIDS Epidemic

State Level HIV/AIDS Bodies

The State bodies in charge of designing and implementing AIDS policies are the National AIDS Committee (CONASIDA) and the National AIDS Programme (PNS) of the Ministry of Public Health. CONASIDA is an intersectoral coordination. A lack of financial and human resources has led to inconsistency in the few initiatives that have been implemented and has affected the scope and speed of the State response to the HIV/AIDS problem.

Care and Support Provision

León, Cordero and Vallejo (1997, 5) estimate that, in 1997, 70% of AIDS cases were being cared for in State-run hospitals. However, very few health workers have had training to enable them to provide specialised care to PLHA. Data gathered during this study shows, in particular, a worrying level of discrimination against PLHA by health workers.

Two types of private institution provide specialised care and support services to PLHA: private profit-making organisations and approximately ten non-profit NGOs.

Only social security users (18% of the population), and those eligible to access the police and military hospitals have access to antiretroviral treatments. Even then, treatment may be incomplete and intermittent, depending on the resources available. There are enormous differences in access to treatment between the regions. In July 2000, antiretroviral treatment cost US\$1,600 per month in Ecuador. At the same time, the salary of a public sector employee was on average US\$117 per month.

HIV/AIDS Legislation

An AIDS Law was passed in April 2000. The law aims to guarantee HIV prevention activities, specific State medical care for PLHA and reduce discrimination within society. The law does not penalise institutions which demand compulsory HIV testing as a prerequisite for access to services, employment, etc. It also enables legal action to be taken against people who, aware of their positive HIV status, consciously and voluntarily transmit HIV to another person.

In general, the HIV/AIDS epidemic has not been a public health priority in Ecuador, due to its low prevalence. Torres and Ramón explain the relatively limited State response as follows:

"Firstly (...) [AIDS] has been considered a secondary problem affecting only so-called high risk groups which, in addition, have been stigmatised; secondly (...) in general, health has been sidelined within the policies of structural adjustment (...); thirdly (...) both knowledge of the issue and the technology and funding come from abroad, which has prevented real ownership of the issue and hindered creative reflection; and fourthly (...) there is no strong social movement to make the problem more visible and pressurise the State for political action." (Torres and Ramón: undated, p.9)

International Cooperation

A large number of the official HIV/AIDS initiatives have been headed by international organisations, either bilateral or multilateral organisations or NGOs. However, resources have been limited and actions have lacked co-ordination due to the fact that Ecuador is considered to be a low prevalence country.

Civil Society Mobilisation on HIV/AIDS

Approximately 40 organisations (MPH/CONASIDA, 2000) include HIV/AIDS activities within their work. Most are a response to one-off situations within a local sphere of influence. In general, these organisations share a number of common characteristics: lack of resources, dependence on external funding, an absence of systematic internal procedures, weak internal evaluation and replanning of activities, and limited institutional development, all of which become apparent in different ways and at different levels.

Relations between the organisations are marked by a high degree of competition which, amongst other things, originates in the rivalry caused by the lack of resources existing in the sector. This rivalry means that sustaining coordinated work is difficult. However, various joint initiatives have been developed, such as the PLHA Network, the Network of NGOs working in HIV/AIDS (RetSIDA) and the AIDS Network of Azuay (REDSIDAzúay). These initiatives have gained space within the media and exerted pressure around common issues and proposals linked to the agenda of their membership.

Background to PLHA Involvement in Ecuador

The Ecuadorian government did not participate in the 1994 Paris AIDS Summit and is not a signatory of the final declaration in which 42 States committed themselves to "fully involve non-governmental and community-based organisations as well as people living with HIV/AIDS in the formulation and implementation of public policies."

However, PLHA involvement has increased in the public sphere. There are now PLHA representatives in CONASIDA, although their involvement has thus far not been particularly meaningful.

At community level, the first PLHA self-help groups were informally instigated towards the end of the 1980s both in Quito (Vivir) and in Guayaquil (Dios, Vida y Esperanza). Slowly these groups became service providers aimed at

addressing the needs of the wider community. Their membership evolved with the integration of a large number of health/social workers and PLHA family members into the organisations. This development changed the initial self-help dynamic of the groups.

Subsequently, a number of new groups formed. One example of these new groups, Siempre Vida, was set up by PLHA and affected people who left Dios, Vida y Esperanza because they wanted to maintain a focus on self-help and promote a more central role for PLHA in service design and implementation.

Another organisation with PLHA involvement, Amigos por la Vida, was formed when members of Siempre Vida expressed the need for spaces and services specifically designed for homosexuals.

The first organisations were created to respond to the needs of PLHA that were not being met elsewhere, particularly in areas of care and support. Gradually, some organisations redefined themselves to include: arenas for PLHA empowerment, defence of their rights and advocacy on public policies. There are now half a dozen organisations, actively involved in the struggle against AIDS, which depend on PLHA involvement.

Types of PLHA Involvement in Community Prevention, Care and Support Activities

Two main models of involvement were identified in the study – self-help and assisted self-help. These types are based on a range of criteria, including:

- **The categories of actors within the organisation:** PLHA, affected persons, health workers, social workers.
- **The roles of the actors:** two roles are defined, that of provider (of services, decisions, time, money etc) and that of user or receiver. Some actors may be both providers and users at the same time.
- **Areas of involvement:** strategic organisational decision-making (decision-making bodies), design and planning of the organisation's activities and services (technical bodies), implementation of activities and services, use of services.
- **The level of prominence:** this applies to the service providers and describes their involvement.
- **The visibility of the actors:** how they are identified publicly through their relationship with HIV/AIDS.

Self-help

- The majority of actors in the organisation are PLHA and affected people.
- Both PLHA and affected people play the dual role of service provider, (through involvement in the implementation of different services in the foundation) and service user, (they may also benefit from these services, for example by participation in the self help groups). The primary activities are support, prevention and advocacy. Care is offered indirectly through a system of referral to health workers with whom the NGO has contact.
- PLHA and affected people are involved in the organisation's strategic decision-making and in service design and planning.
- PLHA and affected people are very visible within the organisation and some have a high level of visibility outside the organisation, including in the media.
- The defence of PLHA rights is also a priority for the organisation.
- The self-help model is "open" because PLHA and affected people who do not belong to the organisation can also use their services.
- In addition, it is not self-help among PLHA alone but among PLHA and affected people.

In this type of organisation, the legitimacy of PLHA as service providers is based, above all, on their practical knowledge and experience of HIV/AIDS; life with HIV/AIDS and sometimes, life with a person living with HIV/AIDS. In some cases, this practical knowledge has been supplemented with training and the acquisition of theoretical knowledge. Health workers contribute their experience in areas where significant technical experience is required, such as medical care.

Assisted Self-help

- The actors are both PLHA and affected people and health/social workers.
- PLHA are involved as service providers in care, prevention and advocacy activities.
- The affected people who offer services are not users of the NGOs services, nor do the health and social workers use the services; they are only providers. There are no HIV positive health and social workers amongst the service providers.
- In spite of their involvement, PLHA do not take a leading role in strategic decision-making or design and planning of services and activities within the organisation. Their involvement may be nominal in such areas.

- It is the health and social workers who design and plan services and take strategic decisions.
- Levels of PLHA visibility vary considerably, from an almost complete invisibility inside and outside the organisation to visibility of some PLHA both inside and outside the organisation.

In this type of organisation, PLHA can be both providers and users at the same time, and thus the organisation still falls within the self-help model. However, PLHA do not hold managerial or decision-making power within the organisation. They do not take the initiative in the self-help process; these groups are organised by the professionals. For that reason, these groups have been defined as assisted self-help.

In general, there is some rivalry between the “professional” experts and the “HIV positive” experts, whose experience is personal and empirical. The legitimacy of health workers as service providers is based on their technical, theoretical or practical knowledge, and on the level of skill they have gained through their professional training and experience. It is thus difficult for them to accept the “alternative” experience of PLHA and this may be one of the reasons why they restrict PLHA access to technical and decision-making arenas.

It should be noted that the two organisations in which assisted self-help was observed were originally set up by PLHA and operated as self-help groups until the involvement of professionals and/or the families of PLHA. Following the death of the founders, and as the organisations began to extend the services they were offering, these professionals and/or families took on a more prominent role than the PLHA.

It is also interesting to note that the organisation in which unassisted self-help was observed was established by PLHA and affected people who left the organisation they were originally involved in because they were unhappy with the lack of involvement in the organisation's strategic decision-making and in service design and planning. There are many examples of this phenomenon in different countries, whereby PLHA and/or affected people who are “organised” by professionals within an NGO break away to create their own self-help organisation.

The study also included one NGO in which PLHA are purely the users of care and support services. This organisation corresponds to a professional model of service provision, a traditional structure in which all the service providers are social and health workers, who also design and plan services and take strategic decisions.

Impact of PLHA Involvement

Involvement should be encouraged when it has positive effects. The main reason to analyse PLHA involvement in NGO activities is thus to assess the impact it can have at different levels, such as:

- the quality of life of the PLHA involved
- the activities and services of the organisations and the quality of life of the beneficiaries
- the structure and functioning of the organisations
- the family and the community.

The study reveals both the positive and negative impacts of PLHA involvement at these different levels.

The study shows the opinions of the informants in relation to the impact of involvement, whether this impact is perceived or real. In fact, PLHA involvement is often scarcely visible and its impact is hard to evaluate.

Impact on the PLHA Involved

Positive Impact

“Personally, it has helped me a great deal; I learned to live with the illness and I think this is quite an achievement (...) I accepted the illness and I know that at any moment I may move into a terminal phase and I have accepted that.” (HIV positive service provider – Siempre Vida)

- ✓ Greater acceptance of being HIV positive by getting to know other PLHA who have a normal and productive life, and increased self-esteem.
- ✓ Access to more information and wider knowledge of different aspects of HIV/AIDS.
- ✓ Greater access to treatment and medicines through information and increased contact with other organisations.
- ✓ Increased respect and recognition from others through more visible involvement.
- ✓ The NGO offers a safe space in which PLHA can prepare to deal with the world outside.
- ✓ Freedom to be oneself and give up living a ‘double life’ through increased visibility as a PLHA.

Negative impact

"Of course I suffer because I make visits, for example, to see the needs, to see people, to be there at the end of their life, this hurts me a lot but I've learned to live with it..." (HIV positive service provider – Dios, Vida y Esperanza)

- ✗ "Mirror effect": this is the emotional impact on asymptomatic PLHA who identify with sick people or those in a terminal stage and who think that their health may deteriorate in the same way.
- ✗ Feeling used by the organisations when they're involved in activities.
- ✗ Dealing with discrimination, particularly when involvement is visible.
- ✗ Contrast between the free and supportive space of the organisation and the reality outside, where PLHA face stigma and discrimination.

Impact on the Organisations' Activities and Services

Positive Impact

If the users are cared for by PLHA, the services provided can go beyond the practical needs of PLHA to providing a better quality of care which responds more appropriately to the emotional needs and expectations of PLHA.

"I felt so alone, I thought I was going to die there and then...the group helped me to get to know other people in the same situation and this has been a great psychological support...so I haven't been to a psychologist but I have been helped by seeing a group of people in the same position; this has helped my self-esteem." (HIV positive service user – Siempre Vida)

The impact of PLHA involvement on specific activities, mentioned by those interviewed included the following areas:

Self-help

- ✓ PLHA gain knowledge by sharing with other PLHA.
- ✓ PLHA share experiences, ideas, solutions.
- ✓ Empowerment and group work are boosted, particularly when the self-help activities are well organised.

Prevention – Awareness-raising

- ✓ PLHA are normal, active people.
- ✓ Anyone can be at risk from infection.
- ✓ Greater credibility in the information because it is provided by PLHA.
- ✓ A real, human face to HIV/AIDS.

Counselling – Support

- ✓ Greater credibility in the information provided.
- ✓ PLHA can share experiences, problems and solutions.
- ✓ The HIV positive user can identify with the PLHA counsellor, empathise more easily with him/her, which facilitates the development of a more trusting relationship.
- ✓ Seeing other active and productive PLHA can be inspiring for newly diagnosed PLHA accessing services for the first time.
- ✓ PLHA counsellors have a greater understanding of the problems and needs of the PLHA user.

"The first counselling I received was in hospital, and it was with an HIV positive person. He identified himself as such, and so...the first thing you do is say: 'Well, if he is like that ... and if he's had the virus so long, ... I can be like that too'." (HIV positive service user – Siempre Vida)

Negative Impact

- ✗ The PLHA counsellor can give technically incorrect information if s/he has not received suitable training.
- ✗ The PLHA counsellor can try to impose solutions based on his/her own experience, which may be inappropriate for the user.
- ✗ A relationship of dependency may be created if the user identifies too closely with the PLHA service provider.

Impact on the Operation of the NGO

Positive Impact

- ✓ The existence of PLHA undertaking activities and/or running organisations leads to greater internal and external credibility.
- ✓ The experience of PLHA enables a better response to be given to the needs of PLHA and improvements to be made in the scope and quality of services.
- ✓ Greater awareness amongst those members of the organisation who are not HIV positive.
- ✓ The organisation increases and strengthens its human resources.

"Working with PLHA breaks down all the myths, you liberate yourself from the 'you're going to get AIDS working alongside him or her or because you hugged someone or gave them a kiss' syndrome...and you become a human being." (Seronegative service provider – Vivir)

Negative Impact

- ✗ Problems of discrimination because the organisation has PLHA involved. This may have an effect, for example, in the allocation of funds, or in the search for premises from which to operate, etc.
- ✗ The contribution of seronegative people may be under-valued, creating an inverse discrimination within the organisation.
- ✗ When the state of health of the PLHA deteriorates or they die, there may be a lack of continuity or disruption to activities.

Impact on the Family and the Community

Positive Impact

- ✓ Improved information about HIV for relatives and loved ones because PLHA who are involved in activities can give them greater information.
- ✓ Improved perceptions of PLHA; realisation that PLHA can be active and productive.
- ✓ Decreased sense of isolation and stigma for the family because they know other PLHA and they realise that PLHA are ordinary people.
- ✓ Greater acceptance of HIV positive people and better integration into the family and community.
- ✓ For affected people that are involved in the NGOs, the contact and exposure to experiences of HIV positive colleagues is a way of learning how to relate to their loved ones, how to give them support and care for them.

Negative Impact

- ✗ PLHA and their families may have to confront different levels of stigma or discrimination, particularly if their loved one's positive serostatus is visible.

Conclusion

Training/capacity building is the single most important factor in promoting or maximising the positive impacts whilst reducing the negative ones.

Factors that Limit PLHA Involvement in Community Organisations

The frequency with which different factors were reported by different types of people was analysed and they were classified into three categories:

- social factors
- individual factors (factors specific to PLHA)
- institutional factors (factors specific to NGOs)

Some of these factors are given below.

The **social factor** reported by the majority of informants was the stigma and discrimination of PLHA in Ecuadorian society.

The **individual factors** that were most often stated were the following:

The fear of stigma and discrimination: PLHA fear that by being involved in AIDS organisations they may be identified as PLHA and discriminated against in family, institutional and work spaces. Many informants explain that confidentiality with regard to serostatus is a necessary condition for involvement. The study data confirms that a certain level of visible involvement can lead to discrimination against PLHA but, on the other hand, there are also examples that show that involvement can encourage PLHA integration within the family and the community.

"We have people who cannot be involved due to the simple fact that they may be visible, people may find out about their positive serostatus in their work place or in their social circle." (HIV positive service provider – Siempre Vida)

The health problems of PLHA may make their involvement difficult according to many informants who think that only asymptomatic PLHA can be actively involved. In reality, the study shows that the majority of HIV positive service providers in the two associations with greatest active PLHA involvement are not asymptomatic PLHA. In addition, it was shown also that, on average, more than 60% of PLHA in these groups have access to antiretroviral treatments which reduce susceptibility to illness.

The lack of financial resources among PLHA is another factor often mentioned by the informants. In fact, many HIV positive beneficiaries of the NGO's services are very poor and would not have the money to pay the

necessary transport costs for even a minimal involvement in the organisations' activities. It was observed that the majority of PLHA service providers in the organisations participating in the study belong to the lower middle classes, having completed secondary level education.

Psychological factors, such as the lack of acceptance of seropositive status, the fear of knowing people with AIDS and also the lack of motivation to do voluntary work in HIV/AIDS were also mentioned.

The **lack of time** on the part of women and those in full-time employment was also mentioned.

At the level of the NGOs, the main **institutional factors** that limit involvement were given as the following.

A lack of planning and opportunities for involvement: the issue of involvement has not been considered in NGOs run by health and social workers and this has made establishing concrete policies and actions difficult. In addition, many organisations have a centralised executive which does not facilitate the involvement of new service providers, HIV positive or not.

Paternalistic attitudes towards PLHA: in some organisations, PLHA are still perceived as the recipients of services and benefits. There is a preconception that PLHA lack ability due to their level of education or experience.

It was observed that in the assisted self-help organisations, the consequence of this attitude is an absence of opportunities for PLHA to run activities and the majority of PLHA are involved only as the implementers of simple tasks. There are insufficient processes for the integration and training, in particular, of PLHA who are strongly motivated but who have no experience in service delivery.

In some cases, this situation demotivates PLHA, who may feel used and may withdraw from the organisation leading to the creation of new organisations, as already noted.

"They suggested to me that I could come and help but when, for example, I came yesterday afternoon, they didn't know what I could do...I don't know what I can do or how I can help." (HIV positive user from an association in Quito)

The majority of NGOs have not developed gender policies to respond to the specific needs of women and heterosexual/homosexual men or to encourage the involvement of these groups. For example, there are no childcare facilities in place to enable women's involvement. Those interviewed stated, in addition, that homophobic attitudes still exist.

The data from the study suggests the following profile of involved PLHA: the vast majority are men of working age, between 30 and 45 years old, with a secondary level of education, workers or with their own business in the informal sector and with limited financial resources. Almost half are homosexual or bisexual. In general, they began as NGO service users before becoming involved in support, prevention and advocacy activities. It seems that it is more difficult for other categories of PLHA to become involved in NGO activities, particularly women with children and professional people. For these two categories, the issue of visibility is a very important factor, possibly for different reasons. The lack of time, due to child-care responsibilities or work, prevents greater involvement on the part of women with children and professionals of both sexes.

A Summary of the Main Advantages and Disadvantages of Self-help and Assisted Self-help

During the data analysis workshop, the advantages and disadvantages of each type of involvement were established with the participating organisations. Based on a comparison of this information and the rest of the data collected, the researchers analysed the main advantages and disadvantages of self-help and assisted self-help, identifying the following:

- For self-help to work, the PLHA that are providing services need to have the necessary capacity and, when they do not, good technical training is essential. These training processes can be long but they enable the provision of quality services and an increase in PLHA self-esteem. Training may be more intensive for PLHA to be involved in project design.
- In general, self-help requires good experience running an organisation. If the PLHA founders do not have this experience, external support will be required.

- In assisted self-help, the health and social workers run the majority of services and the PLHA are more like “assistants”. The PLHA may feel used. A lack of training and responsibilities limits the personal development of the PLHA who are involved in activities.
- With adequate training, self-help can be a far more rapid process of PLHA empowerment than assisted self-help.
- Self-help entails a higher risk of physical and psychological burn-out on the part of PLHA who are involved in activities, because of the potential for excessive workloads.
- In self-help, PLHA can design and plan the services according to their own needs. This improves their capacity to respond to the problems and demands of HIV positive users.
- In self-help, PLHA who are involved in all levels of the organisation can be positive role models for HIV positive users and affected people.
- Self-help can lead to a higher level of visibility for PLHA outside the organisation, which may expose them to greater discrimination. The PLHA therefore require adequate psychological preparation.
- Assisted self-help can be a stage of psychological preparation and learning for PLHA, which can then lead to greater involvement.

Gender and Involvement

A gender perspective, including the criterion of sexual orientation, was a crosscutting theme of the study at various levels. Firstly, note was made of the organisations which include a gender perspective in the provision of services to PLHA and affected people.

Secondly, the issue of involvement was analysed in relation to gender and sexual orientation, such as, for example, obstacles to the involvement of certain groups, and strategies for overcoming these. Finally, the involvement of certain groups within NGOs (women, male homosexuals) was considered in terms of the adaptation of services to the needs of these groups.

The issue of gender was very new to the NGOs. One of the study's findings was that the majority of service providers interviewed consider the needs of women, heterosexual and homosexual men and bisexuals in relation to HIV/AIDS to be the same and thus do not consider that specific services could be offered to respond to their needs.

Some of the Specific Gender Needs Identified by the Study

For HIV positive women

- More information on motherhood as there is a tendency to rule out the possibility of pregnancy for HIV positive women
- Specialist gynaecological and obstetric care
- Counselling by other women
- Social support for affected children
- Training to carry out productive activities
- Appropriate language to tackle issues such as safe sex and use of condoms

For affected women

- Greater information (in the case of partners of PLHA) on how to have sexual relations without becoming infected, and care of PLHA relatives
- Psychological support for the family

For HIV positive heterosexual men

- Greater access to condoms
- Appropriate information on safe sex
- Counselling for partners

For HIV positive homosexual and bisexual men

- More open and tolerant attitudes towards homosexual and bisexual men
- Confidentiality with regard to their serostatus and also their sexual orientation
- Specific counselling and/or in pairs
- Non-discriminatory medical care
- In the area of prevention, a language and content adapted to their sexual practices

As the organisations have not identified these needs, there is no structured response at the institutional level. However, there are individual responses on the part of service providers to some of these needs, influenced by their own professional or personal experience, including their sex, sexual orientation and serostatus.

The group which receives the lowest specific provision is homosexual and bisexual men, due to their limited social visibility, particularly in the interior of the country, (Sierra)³. The NGO which has male homosexual service providers achieves greater trust and rapport with homosexual service users. The other NGOs sometimes refer users to other organisations working exclusively with sexual minorities and HIV/AIDS.

"We have a different mentality to straight men, and so if they involve us in discussion we take it as chit chat (...) but if they give us something specific to our needs, we will take it more seriously and we might be able to do prevention (activities)." (Homosexual HIV positive service user – Siempre Vida)

There are women in all of the organisations, involved both in implementing activities and in decision-making and service design.

The study shows that there is no direct relationship between the involvement of HIV positive women and homosexual men in an organisation and an institutional reflection on the adaptation of its services to the specific needs of these groups. A process of awareness-raising at individual and organisational level on the issue of gender is required.



A member of Siempre Vida Foundation providing peer support, Guayaquil, Ecuador

Conclusions: Encouraging PLHA Involvement in NGOs

There are various levels of self-help and assisted self-help. Each type of involvement has advantages and disadvantages for the PLHA involved in the organisation, for the users and for the organisation itself. It is important for each NGO in which there is or may be PLHA involvement to draw up a list and analyse these advantages and disadvantages in order to choose the most appropriate form of involvement for all.

In fact, PLHA involvement is a process for which NGOs can plan. Planning requires the involvement of the various actors within the organisation, a good knowledge of its structure and functioning and a definition of the type of involvement desired and the goal of involvement.

Organisations need to incorporate the "gender" variable into their work so that they offer activities and services specific to women, heterosexual men and homosexual men, along with spaces for involvement. Thus responding to specific demands and needs could promote greater involvement on the part of all users.

PLHA involvement in NGOs has a largely positive impact at different levels. One of the basic conditions for promoting PLHA involvement is the training of those involved, not only in basic technical aspects of HIV/AIDS but in issues of personal and organisational development.

Other essential conditions include the psychological support of people involved in the organisations and the preparation of staff members to work with PLHA under equal conditions.

³ The country is usually divided into "Sierra", the region of the Andean mountains in the interior of the country and "Costa", the coast.

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Doris Herrera and Norma Velasco (researchers in Ecuador), Christophe Cornu (International Study Coordinator)

Acknowledgements

Alejandrina Maldonado (Research Assistant). CEPAR and Kimirina, project partners in Ecuador, for their logistical, administrative and technical support. Dr Julie Pulerwitz (Horizons/Path) for her participation in the data analysis. Alejandra Trossero and Kate Gibson (International HIV/AIDS Alliance).

The profile of each organisation participating in the study is available, along with the general report of the study's results, from the Alliance Secretariat and Kimirina.

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